CHAPTER 6: LINKAGES TO OTHER RELATED SERVICES

This Chapter describes how the strategies contained in this plan to prevent persons from becoming infected or infecting others (primary prevention) are linked to activities to prevent or delay the onset of illness in persons who are HIV infected (secondary prevention). See Definitions on page – of this Plan.

Why is the Link from Primary Prevention to Secondary Prevention Services Important?

Recent advances in HIV treatments have significantly impacted the lives of people with HIV and the approaches to responding the epidemic. HIV medications have delayed the onset of AIDS and offer hope of reducing transmission to others by lowering viral loads and possibly diminishing one's infectiousness. However, there are many challenges for persons to take their medications such as side effects, multiple pills, other competing life events, denial, or economic cost. On-going prevention support services must be available to help HIV infected persons be successful with taking medicines, and to help them adopt and maintain healthy behaviors. Early identification of HIV status and linkage to HIV care and treatment services is essential for this to occur.

Many persons at greatest risk for HIV or who are HIV infected have multiple health and social service needs. Many persons may have "co-morbidities" such as HIV and substance use or TB. Needs assessments in South Carolina consistently indicate a high likelihood for depression among persons with HIV, particularly women in rural areas, creating a need for mental health and counseling services. A significant proportion of our target populations are likely to be uninsured or underinsured and have low-incomes, creating needs for supportive services such as transportation, food, housing, job assistance training.

Prevention and care providers must acknowledge and recognize that a "holistic", client-centered approach is essential in order to increase effectiveness of both primary and secondary prevention. A recently discharged HIV infected inmate is not likely to keep an initial appointment with the local HIV care provider when he/she has no job to obtain food, or reverts to substance use once back in the streets. Or, a woman in a dependent relationship with a partner prone to domestic violence is not likely to be successful in negotiating safer sex until relationship issues are confronted.

What are the key challenges for effective linkages?

It is important for providers to recognize that even though essential services exist in our state, there are systems-level, provider-level and client-level barriers that may impede successful linkages. Systems-level barriers may include not operating services at times or days convenient for clients; locations that are difficult for clients to reach particularly in more rural areas, or lack of staff and resources to meet the demand/need for services thus turning-away clients, having waiting lists, or not being able to meet all a client's needs. Provider-level barriers may include lack of skills to engage clients and assess the myriad of psychosocial and health needs; lack of

knowledge of other service systems preventing active referrals, or lack of cultural competence skills to effectively communicate with clients. Client-level barriers may include lack of resources for transportation to services; denial of their illness, other competing issues, fear of stigma or lack of confidentiality preventing them from making or keeping regular appointments, or lack of knowledge that services exist or how to successfully access services.

To better identify and address these challenges, the state involves persons living with HIV in planning and delivery of services at the local and state level. The Ryan White Title IV Consumer Involvement project hires multiple parent advocates at each regional center to enhance cultural competence, increase consumer involvement in advocacy roles, planning and evaluation, and provide a supportive role to maximize medication adherence.

What are the Key Linkages and Challenges in South Carolina?

South Carolina has developed an extensive infrastructure of linkages between primary and secondary HIV prevention services. Many services are integrated making it easier for persons to receive a range of prevention services such as HIV counseling and testing, STD diagnosis and treatment, TB screening and reproductive health services. Additionally, many agencies in South Carolina are lead agencies for both prevention and HIV care services, allowing for a seamless transition for those persons diagnosed with HIV. Integrated services can facilitate both effectiveness and efficiency of primary and secondary prevention efforts.

To facilitate linkages, information about accessing counseling and testing services, other prevention agencies, Ryan White, HOPWA and other care services is available through the toll-free state AIDS Hotline operated by DHEC STD/HIV staff. Hotline staff have updated it's electronic database of all HIV related services by county using the same software that local care consortia /HOPWA sponsors use which will allow local case managers to access resources listings electronically as well as provide any updates. This database is used to publish the "Statewide HIV/AIDS Resources Information and Network Guide' (SHARING) which is distributed to primary and secondary prevention providers in the state. SHARING is also available through DHEC's Internet site, www.scdhec.net/. The guide lists education/prevention, outreach, counseling and testing services, primary care, supportive services, social and legal services by category in each county in the state. It describes statewide services available such as Ryan White funded programs, housing assistance, Department of Alcohol and Other Drug Abuse Services, Department of Mental Health, Community Long Term Care (Medicaid), church care teams, etc. The guide is used by prevention collaborations, community based organizations, youth initiatives, statewide hotline staff, counseling and testing staff and consortia staff to identify existing services and refer individuals to appropriate available services.

Another recently completed tool is the Resource Directory developed by the Title IV, African American Youth Project. The directory was developed by key youth serving organizations in the Columbia area to enhance the referral system for adolescents from agencies where services are accessed. The directory provides a youth-friendly description of each service; the directory will be available through local agencies, providers and will be on the internet.

Below describes key linkages for the following essential related services:

- HIV testing, counseling and referral services
- STD, TB, Hepatitis and Reproductive Health Services
- HIV Care and Support Services
- Perinatal HIV Prevention and Care Services
- Homeless Prevention Services (Housing Opportunities for Persons with AIDS -HOPWA)
- Substance abuse treatment Services
- Mental health services
- Correctional Systems

1) HIV Counseling , Testing and Referral

The primary linkages to HIV counseling and testing services in South Carolina are made though:

- Partner counseling and referrals
- AIDS Hotline referrals
- HIV Prevention Collaborations/community organizations providing health education/risk reduction
- Outreach strategies by community organizations, Ryan White Title III providers, DHEC mobile screening
- Routine HIV screening in STD, TB and Family Planning clinics
- Routine HIV screening for pregnant women
- HIV testing in several alcohol and drug abuse facilities
- Public information/media awareness
- Physicians/primary care providers
- Blood/plasma centers

HIV counseling and testing services are available in each county health department. Nearly one-third (30%) of the annual number of newly reported persons with HIV in the state is diagnosed through the county health departments. Over 37,100 clients received counseling and testing services during calendar year 2000 (this includes those clients routinely screened during other STD, TB or family planning services. Screening for syphilis and tuberculosis is provided for all newly identified HIV infected clients and referrals are made for treatment within the health department if necessary. All newly diagnosed HIV infected clients are offered free CD4 and viral load tests and referrals are made to community health centers, private physicians, local Ryan White care consortia or the pediatric HIV/AIDS care centers, and the state AIDS Drug Assistance Program. Staff also make referrals for drug treatment services, counseling, support groups, AIDS service organization services, Medicaid applications and other services.

In addition to county health department sites, HIV counseling and testing services are provided through: 1) five HIV prevention collaborations through contracts with the STD/HIV Division, 2) several alcohol and drug abuse treatment agencies, 3) one CDC-direct funded community organization in the Columbia area. These organizations all have either contracts or

memorandums of agreement with DHEC and include referrals to primary care, partner counseling and referral services, and other services as appropriate.

HIV counseling and testing services are also provided by primary care centers, and the 5 Ryan White Title III projects, which directly link HIV, infected persons to primary care.

2) "One Stop" STD, TB, Hepatitis and Reproductive Health Services

DHEC STD and Family Planning staff have been cross trained to provide integrated services allowing for "one stop shopping" for clients. The training includes HIV counseling and testing and information on referrals to care consortia for clients testing positive. STD screening and treatment services are provided at each county health department. Based on risk assessments, STD clinic clients are routinely offered HIV testing and counseling. Hepatitis B vaccines are provided free to persons born in 1976 or after if being evaluated for STD or HIV. Female STD clients also may receive reproductive health services such as pelvic exams, pap tests, and contraceptives. Family planning clients attending county health departments are routinely screened for chlamydia, gonorrhea and are offered HIV testing based on risk assessment.

TB services are also provided at each county health department and all clients with positive PPD tests are routinely offered HIV screening. TB/HIV co-infected clients are case management by local public health staff who often provide direct observed therapy for both TB and HIV related treatments.

To increase access to syphilis, HIV and other STD screenings, DHEC initiated mobile van screenings in counties of highest syphilis prevalence in 2001. These counties include Richland, Sumter, Florence, Lancaster, and Horry. Depending on staff resources, services available through the van will include syphilis, HIV, chlamydia, gonorrhea screening and treatment; pregnancy testing; blood pressure screening. Outreach education and referrals are provided as appropriate for follow-up treatment or primary care services.

3) HIV Care and Supportive Services

The primary linkages to HIV care and supportive services in South Carolina are made though:

- Provider referrals from HIV counseling and testing sites
- Referrals from physicians, primary care clinics, hospitals, and other providers
- Partner counseling and referral services
- AIDS Hotline information
- Direct referrals from Ryan White programs' case managers
- Direct referrals for HIV infected inmates discharged from Department of Corrections

South Carolina has developed an HIV/AIDS services infrastructure which provides a continuum of primary care, supportive services and other related services for persons with HIV disease who are uninsured or underinsured. Primary care services are provided either directly or by referral mechanism through the eleven Ryan White Title II care consortia, five Title IIIb HIV early

intervention services, and Title IV pediatric care providers. The primary medical care providers include private physicians, Title II funded clinicians, and primary care/community health center physicians. The Title II AIDS Drug Assistance Program (ADAP), pharmaceutical company drug assistance programs, and Medicaid provide access to therapies.

Substance use treatment is primarily provided by the county alcohol and drug abuse facilities upon referral by the care consortia providers. Availability of dental services has increased during the past few years with several consortia arranging dental clinics or developing referrals with dental providers. *Mental health services* are provided through the local mental health centers and with a few consortia having social work staff to provide psychosocial assessments and counseling. Dental and mental health services remain two of the needs most often identified as being unmet particularly in rural areas of the state.

Supportive services that enable persons to access and remain in primary care are provided directly by case management staff with the eleven Title II consortia and eleven Title IV pediatric care system sites. Case management services are also provided by Community Long-term Care agencies through the state's AIDS Medicaid Waiver. Other health or supportive services that promote health and enhance quality of life are provided through the care consortia network such as Housing Opportunities for Persons With AIDS, *church-based care teams* that provide emotional support and meals, and AIDS service organizations.

Particular emphasis of all Ryan White Care providers is on increasing access to care and ensuring African American persons with HIV are linked to care services. Estimates of those persons who are in care are based on several sources. Ryan White Title II consortia reported serving 6,651 persons during 2000; the AIDS Drug Assistance Program (ADAP) had 1768 active clients in 2000. Clients served are essentially representative of the epidemic. Consortia clients were 71% African American and 62% male; ADAP clients were 63% African American and 70% male.

The AIDS Drug Assistance Program (ADAP) consistently maintains a waiting list of persons seeking to obtain direct assistance with HIV medications. Increased federal funds have expanded ADAP's ability to serve an increased number of clients during past three years, however, funding is still not enough to meet the need. To address disparities among African Americans, increased federal funding was allocated to states this year to implement activities to ensure African Americans are linked to ADAP services. Additionally, staff are piloting an insurance premium coverage program that has been found cost effective in other states.

Analysis of the state's Supplemental HIV/AIDS Surveillance Project (SHAS) interview data indicates a decreasing proportion of HIV infected survey participants report having no care in past year (41% in 1993/1994 vs 24% during 1998 – August 2000). However, African Americans are more likely to have no care than whites: 26% reported no care during 1998 – August 2000 compared to 11% of white persons. African American men are more likely to have no care than women.

The primary unmet HIV care and supportive services needs continue to be need for mental health/counseling services, substance abuse treatment services, dental care, nutritional counseling, job assistance training/information, pediatric case-management and child care, and innovations to support adherence for medications. There is an on-going need for provider education on clinical care guidelines, HIV management and counseling clients regarding HIV drug treatments.

One of the cross cutting issues identified by HIV care providers is the fact that many people with HIV are non-adherent in taking medications as prescribed and with keeping appointments for medical care. This is rooted in many causes, such as fears of government programs, fear of family members and others learning of their HIV status, side-effects of medications, lack of funds to pay for medications and low self-esteem. Local care consortia are facing ongoing challenges associated with HIV treatment costs and problems with adherence to the extremely complex drug regimens. The Ryan White Statewide Coordinated Statement of Need (SCSN) addressed the issue of HIV drug adherence as one of the priority goals for the state. Solutions include implementing education/counseling interventions for clients and training providers on adherence issues and how to assist clients with psychosocial and environmental support systems to facilitate adherence.

4) Perinatal HIV Prevention and Care Services

This project assures that each child born to a mother with HIV can receive medical care, case management and medications. Medical homes are located in each family's hometown when possible and specialty medical care is provided through three primary sites. Clients served under Title IV of the Ryan White Care Act receive HIV specialty care at one of the three regional tertiary medical care facilities located around the state: Charleston (MUSC), Columbia (USC) and Greenville (GHS-with sister site in Spartanburg SRHS). Each Title IV local case manager in conjunction with a regional case manager is charged with coordinating with representatives from HIV prevention, HIV surveillance, Maternal and Child Health, Mental Health, Substance Abuse, Department of Social Services, HOPWA, Title II care and ADAP, to ensure that every potential client (HIV exposed, infected, or affected) has the opportunity for 100 percent access to high quality specialty and primary health care and zero percent disparity in health outcomes should they receive services.

One of the significant successes in HIV prevention due to a combination of effective treatment and concerted coordination and linkages efforts is reduced transmission of HIV from an infected mother to her infant. Evaluation of perinatal HIV prevention transmission efforts in South Carolina indicate that, overall, pregnant women in South Carolina are being routinely offered HIV testing and for those infected, being offered treatment. This practice has resulted in a decline of the number of HIV infected infants due to perinatal transmission from 15 in the 1994 birth cohort to 4 (preliminary) in the 1999 birth cohort.

In order to maintain these successes and to achieve elimination of perinatal HIV transmission in South Carolina, increased prevention strategies are needed focusing on women who receive

inadequate prenatal care or no prenatal care and on HIV infected women with complex psychosocial issues who may not adhere to recommended antepartum or postpartum therapy and/or care plans. This will require increased provider training, increased coordination and linkages with existing systems of prenatal care providers and institutions, and specialized prevention case management services for HIV infected pregnant women. Recent needs assessment with hospitals, for example, indicate that an estimated 41 % of hospitals offered rapid testing during labor and delivery for women with no or late prenatal care.

As a rural state, access to culturally competent, family-centered, community-based, coordinated care is a challenge. Barriers to care continue to be transportation for clients/families living in rural areas to travel to regional clinics causing many clients to spend at least ten hours between leaving their residence and returning home. Additionally, clients have significant fears of stigma in small towns, in many cases preventing clients from accessing local resources or other financial assistance rather than risk a local agency/staff person to learn of their HIV status.

5) Preventing Homelessness: Housing Opportunities for Persons With AIDS (HOPWA)

Many persons with HIV face increased risks of homelessness due to the impact of the disease on physical health and high cost of care and treatment. The average cost of medications alone per year is $11,000. The Housing Opportunities for Persons With AIDS (HOPWA) grant from HUD provides funding to DHEC to prevent homelessness.

The HOPWA program continues to be a major portion of the delivery system of services to people and families living with HIV. Twelve project sponsors experienced in providing a continuum of care for persons and families living with HIV/AIDS each year who are either homeless or at risk for becoming homeless are recipients of HOPWA funds. Eleven project sponsors provide short-term rent, mortgage and utility payments for persons with HIV/AIDS and their families. AID Upstate, an AIDS Service organization in the Upstate, continues to sub-contract with Project Care to pay for operating expenses for a community residence in Greenville. Eleven project sponsors will provide supportive services. HOPWA project sponsors are all closely linked with the eleven Title II HIV care consortia. This assures a coordinated system of delivery to eligible persons and families with HIV/AIDS.

The recent good economy and HIV medications are allowing persons with HIV to maintain jobs or return to work. Interviews with 679 recently HIV diagnosed persons during 1998 – August 2000, indicate that more persons with HIV are estimated to be employed (61%) compared to previous years; however, the proportion who have insurance coverage has remained less than half (48%). Women are more likely to be unemployed than men during this time period (46% vs 35%). The majority of these individuals were living with family. While this is encouraging, it also often means an entire family may become “at risk” of homelessness due to the financial strain of their family member’s illness. It is also noteworthy that more than one fourth of those interviewed said they lived alone, possibly without any family support. Many persons could not afford housing on their own. Forty three percent of persons had a household income of less than $10,000, suggesting that many persons with HIV/AIDS and their families fall below the poverty

level. Less than 1% of those interviewed were either homeless or living in a shelter, a decline from 2% in previous years.

On-going needs assessments with care and supportive service providers and with persons living with HIV indicate that while there is variance around the state, there is a high demand for adequate, affordable housing. There are long waiting lists for subsidized housing, a lack of low-income, safe, and quality housing for low-income individuals, particularly single men with a history of substance abuse and incarceration. Specific types of housing needed include stable low-income housing, temporary shelters, advanced care facilities for those requiring medical assistance, and a hospice facility. None of the available shelters are prepared to provide quality assisted living for persons with HIV.

Barriers to meeting the underserved housing needs of the HIV infected population include: lack of education about HIV in the community and at the housing agencies; excessively expensive rental housing; community apathy towards persons with HIV; client lack of resources and inability to follow-up; long waiting lists at the housing authority and other facilities; and "burnt bridges" with previous housing providers because of HIV infected clients who were assisted with housing and then behaved inappropriately.

The program is currently planning to sponsor pilot projects addressing long term housing needs. The trends in the epidemic indicate that over the next 5 -10 years there is an urgent need for more affordable housing on a long term basis, particularly housing in areas that provide a safe, healthy environment for families or women with children.

6) Corrections

State-Level Institutions

The state correctional facilities (DOC) currently house all HIV infected inmates in two facilities, one for men and one for women. This enables the DOC to better coordinate care and support services to infected inmates. All new inmates receive mandatory HIV screening and if positive are placed in the designated facility. The SC Department of Corrections estimates having over 600 persons with HIV/AIDS in the state system.

Ensuring a continuum of care for persons who may become incarcerated or who are released from correctional facilities is an emerging issue. An average of about 100 persons or more are released each year. HIV infected inmates who have been taking medications while in the correctional facility need to have access to medical care and medications upon discharge to avoid disruption. DOC staff, state Ryan White Title II and Midlands consortia staff developed a discharge planning system to ensure HIV infected inmates are efficiently linked to the consortia and care services within 30 days of release. This is to ensure a continuity of care and maintenance of therapies currently taken while in correctional facilities. The DOC provides inmates a 30-day supply of medications upon release.

Efforts are on going to assess the impact of this discharge system in successfully linking released inmates to care and supportive services. Many inmates do not keep appointments due to substance use recidivism or struggles for basic needs such as food/housing.

County Level Institutions

HIV/STD screening services are more limited for county/city jail inmates. This is primarily due to lack of financial/staff resources and in some cases, short incarceration time prohibiting inmates who might be tested in a facility from getting results prior to discharge. HIV and syphilis testing is conducted in five ??? county jails in conjunction with syphilis elimination efforts. Partner counseling and referral staff assist in providing test results counseling and referrals to care providers upon release.

Recent needs assessment has been conducted with both state and county HIV infected released inmates to determine their most immediate health and social services needs. Results will be shared with prevention and care providers to develop improved discharge planning systems.

Key Recommendations to Facilitate Linkages from Primary to Secondary Prevention Services:

Both prevention and care providers should have client-centered skills to assess range of health and social needs of clients to make appropriate referrals

Prevention and care staff training should include client-centered counseling skills, including skills in making active referrals

Periodic assessments should be conducted to determine target populations' knowledge of prevention and care services and skills to access and navigate "system".

Coordination efforts should continue among prevention providers, and between prevention and care providers to identify and resolve barriers to linkages to related services, integrate training and needs assessment efforts as appropriate to avoid duplication, and to maximize existing resources.

Providers should explore options to enhance linkages from primary prevention to secondary prevention services by using peers or near-peers as "bridges" to services, incentives, and seamless prevention/care systems when possible.

Develop client-friendly resource brochure to help clients access the primary and secondary prevention services described in this chapter.